

The relationship between sexual activity and sexual function in breast and
gynecologic cancer patients during adjuvant chemotherapy

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Abstract

Sexual problems are associated with greater depression, body change stress, and worse mental health quality-of-life in women who have survived cancer (Levin, Carpenter, Brothers, et al., 2010). Despite a number of studies of sexual activity and function in survivors of cancer, little is known about the natural course of resumption and maintenance of sexual activity following cancer diagnosis and treatment. This project tests the hypothesis that the presence of sexual activity during treatment will predict better sexual function and satisfaction scores at 4 months post treatment initiation when controlling for demographic, disease, psychosocial, and baseline sexual function. Patients (N=79) undergoing adjuvant chemotherapy completed questionnaires prior to, throughout, and 4-months after beginning treatment. In regression analyses, sexual activity predicted desire and arousal at 4 months, however higher satisfaction scores was not associated with sexual activity during treatment. Analyses predicting orgasm did not converge and therefore results were uninterpretable. The relationship between sexual activity and sexual satisfaction is complex and highly personal and more research is needed to understand better predictors of satisfaction. Results suggest that encouraging sexual activity may protect against loss in sexual function during adjuvant therapy. Providers are encouraged to have discussions with patients about their sexual lives alongside other quality-of-life concerns and to offer resources, if needed.

Introduction

Breast and gynecologic cancers are common, accounting for around 40% of new cancer diagnoses in women (Siegel, Miller, & Jemal, 2016). While treatments for these cancers have led to increased survival rates, these very same treatments are known to lead to side effects that may be physically and emotionally debilitating. In particular, survivors of breast and gynecologic cancers are more prone to sexual problems when compared to other cancer survivor groups, as well as healthy controls (Bober & Varela, 2012; Boquiren et al., 2016). The aims of the present study are to determine rates of sexual activity during adjuvant therapy in a sample of breast and gynecologic cancer patients and to test examine the relationship between engagement in sexual activity and sexual function and satisfaction. To begin, an explanation of the treatment of breast and gynecologic cancer is given, followed by an overview of the literature regarding side effects, with a focus on sexual morbidity, following a cancer diagnosis. The overview concludes with a discussion of the theoretical rationale of examining sexual activity as a predictor of sexual function and satisfaction.

There is a large range of potential treatments for breast and gynecologic cancer. Surgical treatment is often the first treatment offered, with secondary, or adjuvant, therapies to follow. Breast cancer patients may undergo breast-conserving surgery (i.e., lumpectomy), removing cancer tissue without removing the entire breast, or a full mastectomy, where all breast tissue is removed. Radical mastectomy is the most extensive surgical treatment, with surgeons removing all breast tissue, surrounding lymph nodes, and underlying pectoral muscles (Chang, Haigh, & Giuliano, 2005). Patients who have undergone mastectomy are able to receive reconstructive surgery through using their own body tissues (i.e., tissue flap procedures) or through breast implants made of saline or silicone. Additionally, nipple/areola tattooing and fat grafting are

available to reconstruct the surface of the breast, although the reconstructed nipple will have no sensation (American Cancer Society, 2017).

Gynecologic cancer surgeries vary widely based on stage and diagnosis, with the most common surgeries including oophorectomy, or removal of one or more ovaries, and hysterectomy, which may include a partial or total removal of the uterus and surrounding connective tissues and structures, including the cervix and parts of the vagina (Berek & Hacker, 2005). For vulvar malignancies, partial or total removal of the vulvar structures, or vulvectomy, may be necessary (Berek & Hacker, 2005).

Adjuvant therapies are common and are meant to attack cancerous cells left behind by surgery. Common adjuvant therapies for breast and gynecologic cancer include radiation therapy, hormonal therapy, and chemotherapy (Berek & Hacker, 2005). Chemotherapy is the use of drugs to kill cancerous cells. Unfortunately, these drugs cannot differentiate between fast-growing cancer cells and fast-growing healthy cells. Thus, healthy cells are harmed along with the cancer, leaving many people undergoing chemotherapy with side effects. The most common side effects for cancer patients undergoing chemotherapy include fatigue, hair loss, easy bruising and bleeding, infection, anemia, nausea and vomiting, appetite changes, constipation, diarrhea, nerve problems, and more (American Cancer Society, 2016; Berek & Hacker, 2005).

Side effects of treatment may lead to high rates of sexual morbidity in these women (Berek & Hacker, 2005). While cancer treatment can produce quality of life concerns in many cancer survivor groups, the nature of breast and gynecologic cancers make them more prone to sexual concerns than other cancer groups (Bober & Varela, 2012). Gynecologic patients, in particular, often experience damage to pelvic and vaginal nerves and tissues due to targeted treatment in and around these areas (Pieterse et al., 2006; Wilmoth & Botchway, 1999). Breast

cancer surgeries often leave patients with changes in sensation in the breasts as well as body image disruption due to potentially disfiguring surgeries (G. M. Frierson & Andersen, 2006; G. M. Frierson, Thiel, & Andersen, 2006). In both breast and gynecologic patient groups, treatments often induce menopause. Due to the associated reduction in hormones, including estrogen, progesterone, and testosterone, menopause is associated with sexual problems including vaginal dryness, dyspareunia, and lack of sexual interest in both healthy women and cancer survivors (Lee, Kim, & Jeon, 2015; McCoy & Davidson, 1985). The effects of treatment-induced menopause are known to create a feedback loop wherein sexual pain may induce a lack of interest in sex, and over time, vaginal atrophy occurs, making sexual activity more uncomfortable if it is attempted again (Bober & Varela, 2012). Further, even side effects that do not initially appear to be related to sexual function may in fact contribute to a patient's function, satisfaction, and desire for sexual activity. For example, heightened anxiety, nausea and vomiting, fatigue, pain and confusion or "chemobrain", are all reported widely in female cancer patients (Levin, Carpenter, & Andersen, 2010). Using DSM IV criteria, as many as 23 percent of gynecologic cancer patients may qualify for major depressive disorder (Thompson & Shear, 1998). Given these unpleasant physical and emotional symptoms, it is unsurprising that women undergoing treatment may find themselves not wanting or enjoying sexual activity.

Among survivors of breast and gynecologic cancers, there are high rates of sexual dysfunction. Under DSM IV criteria, four domains of female sexual function were addressed: desire disorders, arousal disorders, orgasmic disorders, and pain disorders (Zakhari, 2009). Under DSM 5 criteria, female sexual dysfunction is represented over three disorders: female sexual interest/arousal disorder, female orgasmic disorder, and genito-pelvic pain/penetration disorder (American Psychiatric Association, 2013). However, in the available literature,

diagnostic interviews are seldom conducted to assess whether cancer patients meet criteria for a diagnosable sexual dysfunction. Rather, patients are asked to self-report individual sexual problems, generally grouped into desire, orgasm, arousal/lubrication, and pain. Overall, survivors report some level of sexual problems at rates between 70-80% (Boquiren et al., 2016; Raggio, Butryn, Arigo, Mikorski, & Palmer, 2014). This suggests a much higher rate of dysfunction than in the general population, who are estimated to experience sexual problems at a rate of approximately 40-45% (Laumann, Paik, & Rosen, 1999; Lewis et al., 2010). Among cancer survivors, the most highly endorsed sexual difficulty is desire, with many survivors reporting multiple problems (Boquiren et al., 2016; Grimm et al., 2015; Lee et al., 2015; Marino, Saunders, & Hickey, 2017).

In a cross-sectional study of 186 gynecologic cancer survivors between 2-10 years post-diagnosis, sexual problems after cancer are associated with other psychosocial problems, including depression, body change stress, and mental health quality of life (Levin, Carpenter, Brothers, et al., 2010). In regression analyses, sexual morbidity covaries with depressive symptoms, body change stress, and poorer psychological quality of life when controlling for age, performance status (well-being and ability to accomplish daily activities), and fatigue (Levin, Carpenter, Brothers, et al., 2010). Such cross-sectional studies are limited in that causality cannot be addressed, however, this study suggests that there is a relationship between psychological quality of life and sexual problems. This is supported in the sexual health literature; sexual problems are consistently shown to be associated with depression, anxiety, and relationship problems (Atlantis & Sullivan, 2012; Dunn, Croft, & Hackett, 1999; Shifren, Monz, Russo, Segreti, & Johannes, 2008).

Following treatment, approximately 30-60% of breast and gynecologic cancer survivors are sexually inactive (Grimm et al., 2015; Lee et al., 2015; Marino et al., 2017; Raggio et al., 2014). While sexual problems and inactivity are also common in healthy post-menopausal women, the proportion is smaller and reasons for becoming sexually inactive tend to differ between the groups (Grimm et al., 2015; Marino et al., 2017). In sexually inactive women without a cancer history, the most common reason for sexual inactivity reported is not having a partner, while in survivors of gynecologic cancer, physical problems were the most commonly cited reason, suggesting that treatment effects are more severe than natural menopause (Grimm et al., 2015). Among women who were sexually active before diagnosis with breast cancer, approximately 10% do not resume sexual activity (Lee et al., 2015). In self-reports, the majority of partnered women who become inactive following cancer attribute the change to internal (e.g. pain, vaginal dryness, lack of interest, fatigue) versus external (e.g., partner) factors (Marino et al., 2017). This suggests that problems including sexual dysfunction and other side effects from cancer and its treatments may be important contributors to sexual inactivity.

In an Australian study of partnered female cancer survivors (n=316), investigators found that inactivity was associated with feelings of unattractiveness, feeling unlike a woman, and depressive symptoms (Marino et al., 2017). In studies of the general population, sexual inactivity in partnerships has shown to be associated with lower happiness in their relationship, less social support, and poorer health (Donnelly, 1993; Hess et al., 2009; Karraker & DeLamater, 2013). The Survey of Midlife Development, a survey of a representative sample of adults in the United States, found that sexually inactive women reported lower satisfaction (Thomas, Hess, & Thurston, 2015), a finding that was also reported in Marino et al.'s study of partnered female

survivors (2017). Thus, while sexual inactivity may serve as a useful indicator of sexual problems, relationship difficulties, and related distress in cancer survivors.

Overall, data from survivors of cancer show that treatment can greatly affect their sexual lives. However, there is little known about the sexual lives of women in active treatment. Many women avoid sexual activity during active treatment due to acute side effects, but it is unclear what is unique about women who maintain sexual activity. To our knowledge, there are no studies examining the natural course of resumption of sexual activity following initiation of adjuvant chemotherapy. By understanding the circumstances under which individuals successfully resume or maintain sexual activity during the course of treatment, we may also begin to understand if and when sexual inactivity can be regarded as problematic, rather than a healthy reaction to the acute stresses of cancer diagnosis and treatment.

The aims of this study are to (1) estimate rates of sexual activity during adjuvant therapy in a sample of breast and gynecologic cancer patients; (2) test sexual activity during adjuvant chemotherapy as a predictor of 4-month sexual outcomes (sexual satisfaction, sexual function). Our hypothesis is that the presence of sexual activity during treatment will predict better sexual outcomes at four months. Depressive symptomology, relationship satisfaction, and patient-reported treatment toxicities (e.g., pain, menopausal symptoms, fatigue) are all examined as possible covariates, alongside relevant sociodemographic variables. These variables served as controls in our analyses due to existing literature suggesting that sexual problems and emotional problems are related (Atlantis & Sullivan, 2012; Dunn et al., 1999; Shifren et al., 2008). Unpleasant symptoms, including physical pain, emotional distress, and partner problems may negatively affect women's engagement in and enjoyment of sexual activity, thus we account for these variables in our analyses.

Method

We used a prospective, longitudinal design with repeated measures. Participants (N=80) are female patients with gynecologic or breast cancer treated in the Division of Gynecologic Oncology or the Division of Medical Oncology at the Ohio State University Comprehensive Cancer Center. Participants were accrued following surgery (as applicable) and prior to beginning chemotherapy. Assessments occurred at baseline (prior to initiation of chemotherapy); at the beginning of each chemotherapy cycle, up to six cycles, on the day of infusion, and four months after beginning treatment. The protocol was approved by the Ohio State University's Institutional Review Board.

Measurement

Data from subjects include interview responses, self-report inventories, relevant medical chart data (e.g., diagnosis, treatments), and medical evaluations. Sociodemographic information (e.g., household income, education, employment status, etc.) was obtained from patients via interview.

Sexual Outcomes. Sexual activity, as well as sexual function and satisfaction, was assessed using 11 self-report items. Behaviors (frequency of kissing and intercourse) and global satisfaction items were taken from the Sexual Experiences Scale (Derogatis & Meyer, 1979) and are used to assess the range and frequency of sexual activity. Women are asked to rate the frequency of intimate and affectionate behaviors (e.g., intercourse, kissing) in the past month (at baseline) or since the last assessment (at all follow-ups). We assessed sexual function self-reports of the presence/absence of sexual activity, sexual avoidance, desire, vaginal dryness, lubrication during intercourse, orgasm, and dyspareunia. The present study focuses on sexual activity,

desire, arousal, orgasm, and satisfaction. These items are worded appropriately to assess both heterosexual and lesbian relationships.

Depressive Symptoms. The Iowa short-form of the Center for Epidemiological Studies Depression Scale (CES-D) (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993) was used to assess current symptoms of depression. This short form consists of 11 items rated on 3-point Likert scales from 0=hardly ever or never to 2=much or most of the time. Unique to other measures of depressive symptoms, the CES-D is relatively unaffected by current physical symptoms and is, therefore, commonly used in research on medical populations (Devins, Orme, Costello, & Binik, 1988).

Treatment Toxicities. A patient-reported subset of the NCI common toxicity criteria, v4.0, was used. The Patient-Reported Outcomes CTCAE (PRO-CTCAE) version 1 (Basch & Abernethy, 2011; Basch et al., 2012; Basch et al., 2007; Basch et al., 2006), allows patients to self-report symptomatic adverse events. Items are grouped within body categories. Subscale scores are calculated to reflect the average of items for each body system; scores range from 0-4, with higher scores indicating more life-threatening symptoms. Subscores can be obtained for frequency, severity, and interference of symptoms. We opted to include the interference scores in regression analyses, as it seemed the most relevant in controlling for effect on sexuality.

Procedures

Patient charts were reviewed by study staff to identify eligibility. Patients were diagnosed with stage I-III breast or gynecologic cancer and be scheduled to receive adjuvant chemotherapy. Patients with a prior cancer diagnosis (i.e., women with recurrence) were excluded. Patients were required to be between the ages of 21 and 80 and not have any major psychiatric illness or cognitive deficit that would impact their ability to complete the interview. At a clinic visit prior

to their first chemotherapy infusion, patients were approached by a research staff member and told about the study. If they indicated interest, informed consent was obtained. Questionnaires were then administered by the staff member, who was responsible for marking the participant's verbal responses to the questions. Whenever possible, assessments were completed in full during a clinic visit. When time or distance did not allow, participants were asked to complete the questionnaires over the phone or via mail. Patients were paid \$35 for each full assessment, as well as \$15 for each brief assessment during chemotherapy infusions.

Eighty participants were consented into the study. One participant experienced severe side effects to her first infusion of chemotherapy, which began between consent and the beginning of assessment, and thus did not complete any questionnaires. Of the 79 participants who completed at least some of the baseline assessment, 72 (91%) completed the 4-month follow-up, with the remainder lost to follow-up.

Analysis

Data from baseline (prior to first chemotherapy infusion) assessment and from four months are analyzed. Descriptive data characterize the sample at baseline and 4-months and include sociodemographics, diagnosis, treatment toxicity, depressive symptoms, and sexual function and satisfaction. Baseline and 4-month scores in sexual outcomes of activity, desire, arousal, orgasm, and satisfaction are compared to examine any differences. Differences in means of sexual outcomes at 4 months by diagnosis type (breast cancer vs. gynecologic cancer) are examined. Participants were categorized into either sexually "active" or "inactive" categories based on their responses to the sexual activity items administered at baseline, chemotherapy infusion visits, and 4-month follow-up. If at any of these assessments, the participant reported some sexual activity, they are categorized as "sexually active." We examined between-group

(sexually active vs. inactive) differences in sexual outcomes and covariates. Correlations between baseline measures and 4-month sexual outcomes are reported.

Regression analysis will be used to examine variance in 4-month sexual outcomes. Functional outcomes were dichotomous, and thus will be analyzed using logistic regression. Satisfaction was measured with a continuous Likert scale and will be analyzed using multiple, hierarchical linear regression. For all regressions, the first step will include baseline sociodemographic factors (age, partner status). In the desire model, diagnosis was also added in Step 1 to control for a mean difference in desire between breast and gynecologic diagnosis groups. Due to the fact that diagnosis groups did not differ in any other outcomes, it was omitted from the other models. Step 2 will include baseline depressive symptoms. Step 3 will include disease- and treatment- related variables (e.g., 4-month treatment toxicity). Step 4 will control for baseline score on the specific outcome (e.g., baseline desire is controlled for when predicting 4-month desire). In step 5, we test whether sexual activity during treatment was associated with better sexual function or satisfaction above and beyond these other variables.

Results

Sociodemographics can be found in Table 1. Descriptive statistics of all relevant physical, psychosocial, and sexual variables at baseline and 4 months can be found in Table 2. Pearson correlations were run between controls and sexual outcomes at baseline, and sexual outcomes at 4-month follow-up (Table 3).

At baseline, 27% of participants reported activity in the last month, while at 4 months, 25% of the participants reported activity in the last month. Using our criteria described above, 43% of the sample was sexually active.

In order to explore group differences based on diagnosis (breast vs. gynecologic cancer), independent sample t-tests were run with the outcome variables at 4-months (Table 4).

Difference in sexual desire was trending towards significance and thus was included as an additional control variable in the regression. Otherwise, breast and gynecologic patients were collapsed for the subsequent analyses.

We examined change in sexual activity and sexual outcomes (function, satisfaction) over time (baseline vs. 4-months) using paired sample t-tests (Table 5). Overall, the rates of sexual activity and of sexual function in the sample did not change significantly over the 4 months. Similarly, the mean sexual satisfaction did not significantly change.

Differences between active and inactive groups in sexual satisfaction and function were explored through independent sample t-tests (Table 5). These analyses revealed that differences between active and inactive in all outcomes were statistically significant. The group that engaged in sexual activity at some point during treatment reported experiencing sexual desire, arousal, and orgasm at 4-months more than the inactive group. Similarly, the active group reported higher levels of sexual satisfaction at 4-months.

Logistic regression analyses were run for each dichotomous function outcome. Results showed that the model was significant for desire ($\chi^2(7)=33.454, p<.001$) and arousal ($\chi^2(6)=31.717, p<.001$) (Tables 7-8). Presence of sexual activity significantly predicted presence of sexual desire and arousal at 4-months. Due to low cell count, the model predicting orgasm did not converge and therefore results are uninterpretable.

Linear regression analysis was run for the satisfaction variable. The model was significant [$F(6, 60)=4.672, p=.001$] and predicted 32% of the variance in satisfaction (Table 9). However, sexual activity was not a significant unique predictor of higher sexual satisfaction.

Discussion

The aims of this study were to (1) determine rate of sexual activity during adjuvant therapy in a sample of breast and gynecologic cancer patients; (2) test the presence of sexual activity, alongside relevant controls, as a predictor of sexual outcomes (function, satisfaction) during treatment. Our hypothesis is that the presence of sexual activity during treatment will predict greater desire, arousal, orgasm, and satisfaction scores at 4 months when controlling for demographic, disease, psychosocial, and baseline sexuality function.

In terms of characterizing the sexual lives of the group, we found that 43% of the sample was sexually active at some point during treatment. There were no differences between groups (breast vs. gynecologic cancer) in sexual activity or sexual outcomes. There were no significant differences in activity, desire, arousal, orgasm, or satisfaction rates over time (i.e., between baseline and 4-months), suggesting that rates of activity and function were stable across the first 4 months of treatment. However, when separated into groups by activity, either sexually active or inactive, mean differences in all sexual outcome scores were significantly different, with the active group reporting better outcomes in desire, arousal, orgasm, and satisfaction.

Our hypothesis was supported with regard to desire and arousal. Presence of sexual activity was associated with the presence of sexual desire and arousal at 4-months. We are unable to draw conclusions regarding orgasm, an important domain of sexual functioning. Due to low cell count, results from the model predicting orgasm did not converge and therefore results are uninterpretable. This issue, while problematic for regression analyses, makes conceptual sense as no sexually inactive participant reported experiencing orgasm. Sexual activity was not associated with better sexual satisfaction at 4-months. Thus, it appears that remaining sexually active during

treatment encourages better sexual function, but does not necessarily encourage more personal satisfaction with one's sexual life.

High rates of desire may certainly encourage more activity because it is, by definition, desired by the woman. Similarly, higher rates of arousal may encourage more activity because response to sexual stimuli may provide physical pleasure and prevent sexual pain through the process of lubrication. However, given that our models controlled for baseline function, we can infer that beyond maintenance of pre-treatment sexuality, engaging in sexual activity during treatment is uniquely associated with enhanced desire and arousal at follow-up. This may be due to the fact that engagement in sexual activity may be protective against physical changes (e.g., vaginal atrophy). A lack of sexual activity may diminish desire over time and lead to vaginal atrophy, making future attempts at sexual activity potentially more painful and unpleasant, creating a difficult feedback loop (Bober & Varela, 2012). These results suggest that patients might benefit from engaging in sexual activity during treatment, even if she lacks sexual desire, in an effort to disrupt any feedback loop. Sex is not often discussed by oncology providers, even less so during active treatment (Kennedy et al., 2015; Sporn et al., 2015; Wiggins, Wood, Granai, & Dizon, 2007). These results would suggest that such conversations could benefit patients as they transition out of treatment and into survivorship.

While the total model was significant, sexual satisfaction was not significantly predicted by sexual activity. The relationship between sexual activity and sexual satisfaction is complex and highly personal, with nonsexual factors often holding high subjective importance (Frederick, Lever, Gillespie, & Garcia, 2017; Pascoal, Narciso, & Pereira, 2014; Velten & Margraf, 2017; Young, Denny, Luquis, & Young, 1998). While there is a subset of patients who are dissatisfied with their sexual inactivity, there is also a subset of patients who prefer to be inactive. In fact,

while no active participants reported that their sexual life “could not be better”, four inactive participants did (see Figure 1). While mean scores of satisfaction were significantly higher in the active group, there is a subset of the inactive group that is very satisfied with their lack of activity. This trend may be especially likely in older adult populations (Huang et al., 2009).

Being sexually active does not guarantee better sexual function. While sexually active survivors report better physical quality of life, they also tend to report higher rates of sexual pain than those who are not engaging in sexual activity (Raggio et al., 2014). Further, previous studies have shown that levels of dissatisfaction in one’s sexual life are similarly high among both sexually active and inactive survivors (Marino et al., 2017; Raggio et al., 2014). Engagement in sexual activity may lead participants to be more acutely aware of treatment-related changes in sexual function, such as problems with lubrication and orgasm.

While it is useful to know that engagement in sexual activity predict greater desire and arousal in a therapeutic context, sexual satisfaction is still an important outcome to consider. Patients who do not desire sex or do not experience arousal during sexual activity, but are perfectly satisfied with their sexual lives, are unlikely to seek treatment for sexual dysfunction, nor do they need to. There is normal variation in sexual activity and inactivity is not necessarily indicative of a problem. However, women who are sexually dissatisfied, regardless of their current level of activity, may seek help for these issues. There are a small group of behavioral interventions that have been tested for sexual morbidity after cancer (Brotto et al., 2012; Caldwell et al., 2003; Carpenter & Andersen, in prep). These interventions give multiple strategies to treat and cope with treatment-related sexual problems. Some, including vaginal dilators, moisturizers, and lubricants, address the physical problems that stem from treatment. Interventions often also include cognitive-behavioral therapy and mindfulness strategies. This

reassessment of automatic thoughts regarding sexuality may help to address expectations and dissatisfaction regarding one's sexual life.

Future directions in this study will include continuing follow-up with the participants. Data collection for 8-month and 12-month follow-ups is currently underway, and analysis may give more information regarding our models. This study was limited in that we did not collect sexual histories, nor did we collect data before primary cancer treatment (e.g., surgery). Collecting these earlier data may give a clearer picture of a true baseline, rather than after the patient had already experienced diagnosis and surgery. The sexual health questionnaire included in this study was very simple, as this was not the primary focus of the research. The items included were all dichotomous, posing a problem for analysis of findings, particularly in the domain of orgasm. The questionnaire could be improved through inclusion of continuous measures of sexual function. This adjustment would not only improve our ability to interpret results of the regression analysis, but would give a more complex picture of the experience of sexual function. Future research may expand on questions regarding sexual health, particularly satisfaction. An item asking about levels of distress alongside the question of quality of one's sexual life may further elucidate the relationship between function, activity level, and satisfaction.

Overall, this study lends some support to the idea that sexual activity may be important to maintaining sexual function after cancer, in the domains of desire and arousal. However, there is still much to learn in terms of sexual satisfaction and its predictors. In the meantime, the best method we have to identify sexual dissatisfaction and distress is to ask about it. Healthcare providers are highly encouraged to discuss sexual health with their patients, alongside other quality-of-life concerns, and to offer resources, if necessary.

References

- American Cancer Society. (2016, February 15, 2016). Chemotherapy side effects. Retrieved from <https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/chemotherapy/chemotherapy-side-effects.html>
- American Cancer Society. (2017, September 18, 2017). Breast Reconstruction Surgery. Retrieved from <https://www.cancer.org/cancer/breast-cancer/reconstruction-surgery/breast-reconstruction-options.html>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC.
- Atlantis, E., & Sullivan, T. (2012). Bidirectional Association Between Depression and Sexual Dysfunction: A Systematic Review and Meta-Analysis. *The journal of sexual medicine*, 9(6), 1497-1507. doi:10.1111/j.1743-6109.2012.02709.x
- Basch, E., & Abernethy, A. P. (2011). Supporting clinical practice decisions with real-time patient-reported outcomes. *Journal of Clinical Oncology*, 29(8), 954-956. doi:10.1200/jco.2010.33.2668
- Basch, E., Abernethy, A. P., Mullins, C. D., Reeve, B. B., Smith, M. L., Coons, S. J., . . . Tunis, S. (2012). Recommendations for incorporating patient-reported outcomes into clinical comparative effectiveness research in adult oncology. *Journal of Clinical Oncology*, 30(34), 4249-4255. doi:10.1200/jco.2012.42.5967
- Basch, E., Iasonos, A., Barz, A., Culkin, A., Kris, M. G., Artz, D., . . . Schrag, D. (2007). Long-term toxicity monitoring via electronic patient-reported outcomes in patients receiving

chemotherapy. *Journal of Clinical Oncology*, 25(34), 5374-5380.

doi:10.1200/jco.2007.11.2243

Basch, E., Iasonos, A., McDonough, T., Barz, A., Culkin, A., Kris, M. G., . . . Schrag, D. (2006).

Patient versus clinician symptom reporting using the National Cancer Institute Common Terminology Criteria for Adverse Events: results of a questionnaire-based study. *Lancet Oncol*, 7(11), 903-909. doi:10.1016/s1470-2045(06)70910-x

Berek, J., & Hacker, N. (2005). *Practical Gynecologic Oncology* (4th edition ed.). Philadelphia Lippincott Williams & Wilkins.

Bober, S. L., & Varela, V. S. (2012). Sexuality in adult cancer survivors: Challenges and intervention. *Journal of Clinical Oncology*, 30(30), 3712-3719.

Boquiren, V. M., Esplen, M. J., Wong, J., Toner, B., Warner, E., & Malik, N. (2016). Sexual functioning in breast cancer survivors experiencing body image disturbance. *Psycho-Oncology*, 25(1), 66-76. doi:10.1002/pon.3819

Brotto, L. A., Erskine, Y., Carey, M., Ehlen, T., Finlayson, S., Heywood, M., . . . Miller, D. (2012). A brief mindfulness-based cognitive behavioral intervention improves sexual functioning versus wait-list control in women treated for gynecologic cancer. *Gynecologic Oncology*, 125(2), 320-325. doi:10.1016/j.ygyno.2012.01.035

Caldwell, R., Classen, C., Lagana, L., McGarvey, E., Baum, L., Duenke, S., & Koopman, C. (2003). Changes in Sexual Functioning and Mood Among Women Treated for Gynecological Cancer Who Receive Group Therapy: A Pilot Study. *Journal of Clinical Psychology in Medical Settings*, 10(3), 149-156. doi:10.1023/A:1025402610404

- Carpenter, K. M., & Andersen, B. L. (in prep). SHARE: A psychosexual intervention for women with gynecologic cancer.
- Chang, S. S., Haigh, P. I., & Giuliano, A. E. (2005). Breast Disease. In N. F. H. Jonathan S. Berek (Ed.), *Practical Gynecologic Oncology* (4th ed., pp. 627-667). Philadelphia, PA: Lippincott Williams & Wilkins.
- Derogatis, L. R., & Meyer, J. K. (1979). A psychological profile of the sexual dysfunctions. *Archives of Sexual Behavior*, 8(3), 201-223. doi:10.1007/BF01541239
- Devins, G. M., Orme, C. M., Costello, C. G., & Binik, Y. M. (1988). Measuring depressive symptoms in illness populations: Psychometric properties of the Center for Epidemiologic Studies Depression (CES-D) scale. *Psychology and Health*, 2(2), 139-156.
- Donnelly, D. A. (1993). Sexually inactive marriages. *Journal of Sex Research*, 30(2), 171-179. doi:10.1080/00224499309551698
- Dunn, K. M., Croft, P. R., & Hackett, G. I. (1999). Association of sexual problems with social, psychological, and physical problems in men and women: a cross sectional population survey. *Journal of Epidemiology and Community Health*, 53(3), 144. doi:10.1136/jech.53.3.144
- Frederick, D. A., Lever, J., Gillespie, B. J., & Garcia, J. R. (2017). What Keeps Passion Alive? Sexual Satisfaction Is Associated With Sexual Communication, Mood Setting, Sexual Variety, Oral Sex, Orgasm, and Sex Frequency in a National U.S. Study. *Journal of Sex Research*, 54(2), 186-201. doi:10.1080/00224499.2015.1137854
- Frierson, G. M., & Andersen, B. L. (2006). *Psychological aspects of reconstructive and cosmetic plastic surgery: clinical, empirical, and ethical perspectives* (D. B. Sarwer, T. Pruzinsky, T.

- F. Cash, R. M. Goldwyn, J. A. Persing, & L. A. Whitaker Eds.): Lippincott Williams & Wilkins Philadelphia.
- Frierson, G. M., Thiel, D. L., & Andersen, B. L. (2006). Body change stress for women with breast cancer: The Breast-Impact of Treatment Scale. *Annals of Family Medicine*, 32(1), 77-81. doi:10.1207/s15324796abm3201_9
- Grimm, D., Hasenburg, A., Eulenburg, C., Steinsiek, L., Mayer, S., Eltrop, S., . . . Woelber, L. (2015). Sexual Activity and Function in Patients With Gynecological Malignancies After Completed Treatment. *International Journal Of Gynecological Cancer: Official Journal Of The International Gynecological Cancer Society*, 25(6), 1134-1141. doi:10.1097/IGC.0000000000000468
- Hess, R., Conroy, M. B., Ness, R., Bryce, C. L., Dillon, S., Chang, C.-C. H., & Matthews, K. A. (2009). Association of lifestyle and relationship factors with sexual functioning of women during midlife. *Journal of Sexual Medicine*, 6(5), 1358-1368. doi:10.1111/j.1743-6109.2009.01225.x
- Huang, A. J., Subak, L. L., Thom, D. H., Van Den Eeden, S. K., Ragins, A. I., Kuppermann, M., . . . Brown, J. S. (2009). Sexual function and aging in racially and ethnically diverse women. *Journal of the American Geriatrics Society*, 57(8), 1362-1368. doi:10.1111/j.1532-5415.2009.02353.x
- Karraker, A., & DeLamater, J. (2013). Past-year sexual inactivity among older married persons and their partners. *Journal of Marriage and Family*, 75(1), 142-163. doi:10.1111/j.1741-3737.2012.01034.x

- Kennedy, V., Abramsohn, E., Makelarski, J., Barber, R., Wroblewski, K., Tenney, M., . . . Lindau, S. T. (2015). Can you ask? We just did! Assessing sexual function and concerns in patients presenting for initial gynecologic oncology consultation. *Gynecologic Oncology*, 137(1), 119-124. doi:10.1016/j.ygyno.2015.01.451
- Kohout, F. J., Berkman, L. F., Evans, D. A., & Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D depression symptoms index. *Journal of Aging and Health*, 5, 179-193.
- Laumann, E. O., Paik, A., & Rosen, R. (1999). Sexual dysfunction in the United States: Prevalence and predictors. *JAMA: Journal of the American Medical Association*, 281(6), 537-544.
- Lee, M., Kim, Y. H., & Jeon, M. J. (2015). Risk factors for negative impacts on sexual activity and function in younger breast cancer survivors. *Psycho-Oncology*, 24(9), 1097-1103. doi:10.1002/pon.3772
- Levin, A. O., Carpenter, K. M., & Andersen, B. L. (2010). Psychosocial issues. In J. Berek & N. Hacker (Eds.), *Gynecologic Oncology* (pp. 860-876). Philadelphia: Lippincott Williams & Wilkins.
- Levin, A. O., Carpenter, K. M., Brothers, B. M., Andersen, B. L., Fowler, J., & Maxwell, G. L. (2010). Sexual morbidity as a risk factor for poorer quality of life and psychological outcomes in gynecologic cancer. *International Journal of Gynecological Cancer*, 20(3), 461-470. doi:10.1016/j.ygyno.2007.11.036
- Lewis, R. W., Fugl-Meyer, K. S., Corona, G., Hayes, R. D., Laumann, E. O., Moreira Jr, E. D., . . . Segraves, T. (2010). ORIGINAL ARTICLES: Definitions/Epidemiology/Risk Factors for Sexual Dysfunction. *The journal of sexual medicine*, 7(4pt2), 1598-1607. doi:10.1111/j.1743-6109.2010.01778.x

- Marino, J. L., Saunders, C. M., & Hickey, M. (2017). Sexual inactivity in partnered female cancer survivors. *Maturitas*, 105, 89-94. doi:10.1016/j.maturitas.2017.04.020
- McCoy, N. L., & Davidson, J. M. (1985). A longitudinal study of the effects of menopause on sexuality. *Maturitas*, 7(3), 203-210.
- Pascoal, P. M., Narciso, I. d. S. B., & Pereira, N. M. (2014). What is sexual satisfaction? Thematic analysis of lay people's definitions. *Journal of Sex Research*, 51(1), 22-30. doi:10.1080/00224499.2013.815149
- Pieterse, Q. D., Maas, C. P., ter Kuile, M. M., Lowik, M., van Eijkeren, M. A., Trimbos, J. B., & Kenter, G. G. (2006). An observational longitudinal study to evaluate miction, defecation, and sexual function after radical hysterectomy with pelvic lymphadenectomy for early-stage cervical cancer. *International Journal of Gynecological Cancer*, 16(3), 1119-1129. doi:10.1111/j.1525-1438.2006.00461.x
- Raggio, G. A., Butryn, M. L., Arigo, D., Mikorski, R., & Palmer, S. C. (2014). Prevalence and correlates of sexual morbidity in long-term breast cancer survivors. *Psychology & Health*, 29(6), 632-650. doi:10.1080/08870446.2013.879136
- Shifren, J. L., Monz, B. U., Russo, P. A., Segreti, A., & Johannes, C. B. (2008). Sexual problems and distress in United States women: prevalence and correlates. *Obstetrics and Gynecology*, 112(5), 970-978. doi:10.1097/AOG.0b013e3181898cdb
- Siegel, R. L., Miller, K. D., & Jemal, A. (2016). Cancer statistics, 2016. *CA: A Cancer Journal for Clinicians*, 66(1), 7-30.
- Sporn, N. J., Smith, K. B., Pirl, W. F., Lennes, I. T., Hyland, K. A., & Park, E. R. (2015). Sexual health communication between cancer survivors and providers: how frequently does it

occur and which providers are preferred? *Psycho-Oncology*, 24(9), 1167-1173.

doi:10.1002/pon.3736

Thomas, H. N., Hess, R., & Thurston, R. C. (2015). Correlates of sexual activity and satisfaction in midlife and older women. *Annals of Family Medicine*, 13(4), 336-342.

doi:10.1370/afm.1820

Thompson, D. S., & Shear, M. K. (1998). Psychiatric disorders and gynecological oncology: A review of the literature. *General Hospital Psychiatry*, 20(4), 241-247.

Velten, J., & Margraf, J. (2017). Satisfaction guaranteed? How individual, partner, and relationship factors impact sexual satisfaction within partnerships. *Plos One*, 12(2),

e0172855-e0172855. doi:10.1371/journal.pone.0172855

Wiggins, D. L., Wood, R., Granai, C. O., & Dizon, D. S. (2007). Sex, intimacy, and the gynecologic oncologists: Survey results of the New England Association of Gynecologic Oncologists (NEAGO). *Journal of Psychosocial Oncology*, 25(4), 61-70.

Wilmoth, M. C., & Botchway, P. (1999). Psychosexual implications of breast and gynaecologic cancer. *Cancer Investigation*, 17, 631-636.

Young, M., Denny, G., Luquis, R., & Young, T. (1998). Correlates of sexual satisfaction in marriage. *Canadian Journal of Human Sexuality*, 7(2), 115-127.

Zakhari, R. (2009). Female sexual dysfunction: A primary care perspective. *Journal of the American Academy of Nurse Practitioners*, 21(9), 498-505. doi:10.1111/j.1745-

7599.2009.00440.x

Appendix

Table 1. Descriptive characteristics of the sample

Variable	<i>M / n</i>	<i>SD / %</i>
Age	57.7	5.9
Race*		
Black	5	6.3%
White	73	92.4%
Native American	3	3.8%
Latino	2	2.5%
Education		
Obtained college degree	35	44.3%
Did not obtain college degree	44	55.7%
Marital/Partnered Status		
Single, never married	8	10.1%
Currently married	49	62%
Not married, but in a relationship	5	6.3%
Separated or divorced	13	16.5%
No longer married, widowed	4	5.1%
Annual Household Income		
<\$25,000	9	11.4%
\$25,000-\$50,000	17	21.5%
\$50,001-\$100,000	24	30.4%
\$100,001+	22	27.8%
Don't know/prefer not to answer	7	8.9%
Cancer Type (<i>n</i> = 79)		
Breast	38	48.1%
Endometrial/Uterine	23	29.1%
Ovarian	17	21.5%
Cervical	1	1.3%
Received Surgery	76	96.2%

*Participants were able to choose more than one racial identity

Table 2. Sexual outcome and control measure scores

	Baseline		4-Month		
	<i>M /n</i>	<i>SD / %</i>	<i>M/n</i>	<i>SD/%</i>	<i>Range</i>
Physical					
Treatment toxicity (PRO-CTCAE)					
Interference Subscore	10.4	9.2	9.1	9.2	0-39
Emotional/Psychological					
Depression (CES-D)	6.0	3.8	5.3	3.9	0-18
Sexual Outcomes					
Sexually active	22	28.9%	20	28%	-
Experienced desire	37	49.3%	28	39%	-
Experienced arousal	30	37.5%	26	36%	-
Experienced orgasm	21	60%	18	75%	-
Experienced sexual pain	2	6.7%	8	40%	-
Sexual satisfaction	3.4	2.2	3.21	2.5	0-8

Table 3. Correlations Between Sexual Outcomes and Control Variables

	Desire	Arousal	Orgasm	Satisfaction
Age	-.146	-.108	-.138	.032
College Education	.261*	.259*	.129	-.064
White	-.069	-.087	.058	.026
Partnered	.058	.019	.120	.045
Years w Partner	-.248	-.205	-.143	-.069
Family Income	.142	.166	.267*	.102
Gynecologic Cancer	-.216	-.158	-.032	.048
Baseline Activity (Y/N)	.351**	.396**	.324**	.213
Baseline Desire (Y/N)	.519**	.467**	.454**	.243*
Baseline Arousal (Y/N)	.547**	.480**	.470**	.246*
Baseline Orgasm (Y/N)	.496**	.496**	.409*	.423*
Baseline Satisfaction	.279*	.255*	.333**	.510**
Relationship Satisfaction	.118	.082	.061	.142
Baseline CES-D	-.285*	-.221	-.197	-.256*
4-Month PROCTCAE Interference	-.109	-.073	-.101	-.141
4-Month PROCTCAE Severity	-.080	.030	-.031	-.122
4-Month PROCTCAE Frequency	-.084	.020	-.135	-.151

* Significant at the 0.05 level (2-tailed).

** Significant at the 0.01 level (2-tailed).

Table 4. 4-Month Outcomes By Diagnosis Using t-test for Equality of Means

	Breast		Gynecologic		t-test	p-value
	M	SD	M	SD		
Active	.32	.48	.24	.43	.81	.42
Desire	.50	.51	.29	.46	1.85	.07
Arousal	.44	.50	.29	.46	1.34	.19
Orgasm	.75	.45	.75	.45	.00	1.00
Satisfaction	3.09	2.37	3.32	2.63	-.40	.69

*Significant at $p < .05$ (2-tailed)

**Significant at $p < .01$ (2-tailed)

Table 5. Baseline and 4-Month Paired Sample Statistics

	Baseline		4-Month		<i>r</i>	<i>t</i>
	M	SD	M	SD		
Activity	.30	.50	.29	.46	-.34**	.23
Desire	.51	.50	.41	.50	.52**	1.72
Arousal	.39	.49	.38	.49	-.48**	.24
Orgasm	.87	.35	.73	.46	-.21	1.00
Satisfaction	3.43	2.29	2.46	2.46	-.51**	.46

*Significant at $p < .05$ (2-tailed)

** Significant at $p < .01$ (2-tailed)

Table 6. Outcomes By Activity Using t-test for Equality of Means

	Active		Inactive		t-test	p-value
	M	SD	M	SD		
Desire	.70	.47	.13	.34	-5.98**	.000
Arousal	.70	.47	.08	.27	-7.03**	.000
Orgasm	.86	.36	.00	.00	-4.06**	.000
Satisfaction	4.09	2.00	2.45	2.64	-2.92**	.005

*Significant at $p < .05$ (2-tailed)

** Significant at $p < .01$ (2-tailed)

Table 7. Logistic Regression Model Predicting Desire at 4 Months

Variables	<i>B</i>	<i>SE B</i>	Wald	<i>p</i> value	OR
Age	.025	.036	.464	.496	1.025
Partner Status	-.421	.758	.308	.579	.656
Breast Cancer	-.665	.816	.665	.415	.514
CES-D	-.259	.135	3.707	.054	.771
PRO-CTCAE	.081	.054	2.246	.134	1.084
Baseline Desire	1.313	.874	2.258	.133	3.719
Sexually active	2.543	.880	8.359	.004**	12.721

*Significant at $p < .05$ (2-tailed)

** Significant at $p < .01$ (2-tailed)

All values represent final model statistics.

Table 8. Logistic Regression Model Predicting Arousal at 4 Months

Variables	<i>B</i>	<i>SE B</i>	Wald	<i>p</i> value	OR
Age	.027	.035	.614	.433	1.028
Partner Status	-.558	.755	.546	.460	.572
CES-D	-.138	.124	1.240	.265	.871
PRO-CTCAE	.045	.052	.730	.393	1.046
Baseline Arousal	.498	.848	.345	.557	1.646
Sexually active	-3.449	2.463	1.961	.001**	.032

*Significant at $p < .05$ (2-tailed)

** Significant at $p < .01$ (2-tailed)

All values represent final model statistics.

Table 9. Linear Regression Model Predicting Satisfaction at 4 Months

Variable	β	t	p value	R	R^2	ΔR^2	p value
Step 1				.087	.008	.008	.784
Age	.085	.732	.467				
Partner Status	-.012	-.111	.912				
Step 2				.260	.068	.060*	.048
Depression	-.239	-1.765	.083				
Step 3				.273	.075	.007	.502
Treatment Toxicity	.137	1.030	.307				
Step 4				.555	.308	.234**	.000
Baseline Satisfaction	.453	3.872**	.000				
Step 5				.564	.318	.010	.347
Sexual Activity	.118	.948	.347				

*Significant at $p < .05$ (2-tailed)

** Significant at $p < .01$ (2-tailed)

Values in columns 2-4 (β , t , p) represent final model statistics.

Figure 1. Frequency Distribution of 4-Month Sexual Satisfaction Scores

